Transition of Chronically Ill Youth to Adult Health Care: Experience of Youth With Hemoglobinopathy

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ABSTRACT

Introduction: The purpose of this study was to describe the transition experience, expectations, and concerns of chronically ill youth with hemoglobinopathy (CIYH) (e.g., sickle cell disease) who have transitioned to adult health care.

Method: A descriptive phenomenological study was used to explore the transition experience of CIYH through interviews. A purposive sample of 14 CIYH aged 19 to 25 years were recruited from a large southwestern medical center. The Colaizzi method was used to analyze the CIYH's meaning of the transition experience.

Results: Themes identified were: Reactions to adult care transition ("I don't want to go"), concerns about transition experience ("What's going to happen to me?"), pushed into transitioning to adult care ("Facing the music"), and transitioned to adult care ("Accepting that I had to leave").

Discussion: The findings revealed CIYH's adjustment process, which may facilitate the design of effective interventions to provide uninterrupted medical care as the CIYH transitions to adult health care. J Pediatr Health Care. (2011) *25*, 275-283.

KEY WORDS

Young adult, adolescent, transition to adult care, chronically ill youth, hemoglobinopathy

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The life expectancy of children with chronic illnesses has increased dramatically during the past several decades, with more than 90% surviving beyond their 20th birthday (American Academy of Pediatrics, 1996). However, successful transition of chronically ill youth (CIY) from pediatric to adult care continues to be a difficult and inconsistent process, especially for the CIY with hemoglobinopathy (CIYH) (e.g., sickle cell disease and thalassemia). Transitioning of CIY to adult care may be interrupted by obstacles such as lack of transitional support, limited transitional programs, and resistance to transitioning to adult care from CIY, parents, and pediatric and adult health care providers (Bryant & Walsh, 2009). Often the transitioning experience consists of an abrupt transfer that leaves the youth unprepared for the movement to adult health care (Hauser & Dorn, 1999). Consequently, CIY often do not keep follow-up appointments with the new provider and end up returning to the pediatric providers or the emergency department for health care (Hauser &

Dorn, 1999). Missed adult care appointments by the transitioned CIY can lead to irreversible, preventable complications and even death (Bell, 2007).

To promote uninterrupted medical care as the CIYH transfer to adult care, it is important to understand the holistic transition experience, including the obstacles (e.g., lack of transitional support and programs and resistance to the transition). To uncover the lived experience, the meaning of the transition experience from the viewpoint of CIYH was explored in this descriptive phenomenological study. As the number of CIY living to adulthood increases, effective mechanisms need to be put in place to promote the transition into adult care. An accurate description of their transition experience may facilitate the design of effective interventions to provide uninterrupted medical care in the transfer of CIYH to adult health care, therefore contributing vital and new information to the transitional literature.

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LITERATURE REVIEW

In 1984, the first national focus on health care transition issues (McGrab & Millar, 1989) was presented by the United States Surgeon General during a cohosted conference focusing on the needs of older adolescents with chronic and disabling conditions. The problems of transition were further addressed in a position paper by the Society for Adolescent Medicine (Blum et al., 1993). Also, the American Academy of Pediatrics (1996, 2002) published policy statements emphasizing the important role of health care providers in educating and advocating for youth and their families regarding the transition to adult health care. A significant awareness of the need for programs aimed at helping adolescents transition from pediatric to adult care exists within the literature (Fiorentino, Phillips, Walker, & Hall, 1998; Kennedy & Sawyer, 2008; Lotstein et al., 2009; McLaughlin et al., 2008; Reiss, Gibson, & Walker, 2005; Scal, Evans, Blozis, Okinow, & Blum, 1999; Van Walleghem, MacDonald, & Dean, 2008). Yet, further research is needed to gain understanding of the transition experience of young adults to contribute to the establishment of successful transition programs (Remorino & Taylor, 2006; Telfair, Ehiri, Loosier, & Baskin, 2004).

Even though transitioning to adult care has been identified as a priority, only a limited number of empirical studies have been published on the transition of CIY to adult care, especially within the nursing literature. Studies by Kirk (2008) and Soanes and Timmons (2004) are among the few qualitative nursing studies published on the transition to adult care. Concerns about facing the transition to adult care were reported by both studies that focused on chronically ill adolescents with diabetes, cystic fibrosis, cancer, and complex health care problems from pediatric settings (Kirk, 2008; Soanes & Timmons, 2004). These studies revealed concerns about leaving pediatric health care providers, meeting new providers, the expertise of the new providers, continuity of care, and flexibility of the transition process, including adequate preparation from supportive providers (Kirk, 2008; Soanes & Timmons, 2004).

Another recent qualitative study reported perceptions of adolescent recipients of a heart transplant facing transition who expressed apathy and disinterest toward transitioning to adult care, while their parents perceived transfer to adult care as a negative move (Anthony et al., 2009). Because this was the first mention of transition to the adolescent heart recipients, feelings of apathy and disinterest may indicate the adolescents had not considered that they have a role in the transition process (Anthony et al., 2009), whereas the parents' negative perception of adolescent heart recipients' transition to adult care exemplifies the parents' reluctance to release medical control over the CIY. Because these three qualitative studies focused on the concerns of CIY who are primarily speculating about their future transition experience, there is a need for more studies to focus on the actual experiences of the transitioned CIY.

McCurdy and colleagues (2006) explored the process of transition from the perspective of transferred transplant recipients through use of focus groups. The investigators reported that transplant recipients reflected on their transitioned experience and identified themes of there (pediatric center) to here (adult center), getting ready (transitional preparation), frame of mind (reluctance to leave pediatrics), make it easier (adult center orientation program), and giving back (peer mentor). McCurdy and colleagues reported the use of focus groups, which may have inhibited the transplant recipients from sharing sensitive, embarrassing information and may have promoted group agreement even if individuals had different views. To avoid these limitations, this study focused on ascertaining the transitioned CIYH's experience by using face-to-face interviews.

The majority of transitional science consists primarily of medical studies focusing on the parental and providers' view of the transitional expectations or concerns of the CIY who attend pediatric clinics (Boyle, Farukhi, & Nosky, 2001; Dugueperoux et al., 2008; Lotstein et al., 2009; Peter, Forke, Ginsburg, & Schwartz, 2009; Scal & Ireland, 2005; Telfair, Alexander, Loosier, Alleman-Velez, & Summons, 2004). In a cross-sectional National Survey of Children with Special Health Care Needs